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The Critical Role of Social Workers in Home Based Primary Care

Jennifer M. Reckrey, MD, **Gabrielle Gettenberg**, **Helena Ross, MSW**, **Victoria Kopke, MD**, **Theresa Soriano, MD**, and **Katherine Ornstein, PhD, MPH**

Icahn School of Medicine at Mount Sinai

Abstract

The growing homebound population has many complex biomedical and psychosocial needs and requires a team based approach to care (Smith, Ornstein, Soriano, Muller, & Boal, 2006). The [XX] Visiting Doctors Program (MSVD), a large interdisciplinary home based primary care program in [XX], has a vibrant social work program that is integrated into the routine care of homebound patients. We describe the assessment process used by MSVD social workers, highlight examples of successful social work care, and discuss why social workers' individualized care plans are essential for keeping patients with chronic illness living safely in the community. Despite barriers to widespread implementation, such social work involvement within similar home based clinical programs is essential in the interdisciplinary care of our most needy patients.

Keywords

Chronic illness; geriatrics; psychosocial intervention; social work; homebound; home based primary care

Introduction

As the population ages, the number of individuals living with multiple chronic illness and functional disability will continue to grow. For the over 2 million homebound elders living in the community, barriers to receiving necessary care in the community are significant (American Academy of Home Care Physicians, 2013). Medicare defines being homebound as the ability to leave home only with great difficulty and for absences that are infrequent or of short duration (Centers for Medicare and Medicaid Services, 2013). Compared to their non-home bound counterparts, the homebound have a disproportionately high disease burden, significant functional limitations, and higher mortality (Cohen-Mansfield, Shmotkin, & Hazan, 2010; Kellogg & Brickner, 2000; Qiu et al., 2010). In addition, homebound individuals often require more complex care that addresses not only the medical needs of the chronically ill, but also the psychosocial needs of one isolated from typical social interactions and services (Kellogg & Brickner, 2000). Innovative models of care are needed to address the complex and unique needs of the homebound.

[XX] Visiting Doctors Program (MSVD) is a home based primary care practice in [XX] that provides care to an ethnically and socioeconomically diverse homebound population (K. Ornstein, Hernandez, DeCherrie, & Soriano, 2011; Smith et al., 2006). What started as a small pilot project in [XX] in 1995 has grown into the largest academic home based primary care program in the U.S. and currently cares for more than 1000 homebound individuals

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across [XX] each year. Patients in the program suffer from a wide variety of chronic illness and enter the program with significant symptom burden (Wajnberg, Ornstein, Zhang, Smith, & Soriano, 2013) as well as significant unmet biomedical and psychosocial needs (Katherine Ornstein, Smith, & Boal, 2009) and high levels of caregiver burden (Reckrey, Decherrie, Kelley, & Ornstein, 2013). In order to safely stay at home, these patients need significant support from the entire MSVD team including physicians, nurse practitioners, nurses, administrative support, and social workers.

We believe that the contribution of social workers to the care of patients enrolled at MSVD is integral to the overall success of the program. This manuscript seeks to describe the social work program at MSVD in the context of social work in other community based medical settings and highlight the unique ways that social work is essential in the care of the homebound. We describe the evolution of the social work program at MSVD, the social work assessments developed by the program, and the wide range of clinical activities performed by MSVD social workers. We believe that this will add to the growing literature about the important role that social work plays in caring for patients with complex chronic illness and serve as a model for other practices seeking to integrate social work services into the care of their frail homebound patients. This is particularly important as demonstration projects such as the Independence at Home Act use shared savings models to incentivize providers to provide cost-effective care for frail, medically complex patients at home (Center For Medicare And Medicaid Innovation, 2012; Hayashi & Leff, 2012).

Background: Medical Social Work in the Community

Social workers have long helped meet the health related needs of the chronically ill living in the community. Social workers provided outreach for the medical practices at Massachusetts General Hospital in the early 1900s, were an important part of maternal and child health programs during the Great Depression, and have been an important part of Community Health Centers since the 1960s (Cowles, 2003). Yet today only 13% of social workers report working in the health care field. A minority of these social workers provide care for chronically ill patients in the community: only 44% of social workers in the health care field work outside the hospital, only 9% self identify as working in the field of aging, and only 1.3% are employed by home health agencies (National Association of Social Workers, 2006). While both the social work and medical communities support the idea of integrating social work into community-based medical care (Cowles, 2003), the role of social workers in community medical settings remains poorly defined.

Yet despite the low proportion of social workers working with chronically ill patients in the community, the rationale for social work involvement in medical services is straightforward: as Volland writes, “People who seek medical treatment still need guidance beyond the actual identification and treatment of a medical problem.” (Volland, 1996) Social workers can help identify unmet needs in patients with complex chronic illness and assist them in navigating the complex healthcare system and attaining optimal levels of functioning. As growing attention is being paid to the important ways that care coordination and team based care can improve the quality of care for patients in the community (Grumbach & Bodenheimer, 2004; Institute of Medicine, 2008; Saba, Villela, Chen, Hammer, & Bodenheimer, 2012), support

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for further social work involvement in community based medical settings will likely grow as well.

While the homebound exemplify the complex patients most in need of social work involvement in their routine medical care, this is not the standard of care among the diverse practices and programs providing care to the homebound. Physicians in private practice may independently perform house calls for a subset of the patients they care for. Concierge medicine practices, where an annual fee is paid to cover the costs of enhanced physician services, may offer home based primary care. Yet these models of care rarely employ a multidisciplinary team that includes social workers and instead providers refer to community based services as needed (DeCherrie, Soriano, & Hayashi, 2012). While multidisciplinary teams are more common in academic and Veterans Affairs home based primary care programs, the structure of these teams is highly variable (DeCherrie et al., 2012; Hayashi & Leff, 2012). While physicians may provide direct patient care, they may also function in a supervisory role while other providers such as nurse practicioners and nurses provide the bulk of direct patient care. Home care nurses, therapists, and social workers may be directly employed by the program or may work for independent agencies that provide services by referral. To our knowledge, there is no literature that specifically addresses the role of social work in the primary medical care of homebound adults such as those in MSVD.

Yet the homebound have much in common with other community-dwelling populations where social involvement is more routinely described. We identified three models of social work involvement in community-based medical settings that demonstrate the important role of social workers in the care of individuals with complex chronic illness and we believe that these models can inform the integration of social work into home based primary care programs: 1) disease-specific outpatient care, e.g., dialysis 2) mental health provision in a primary care, and 3) outpatient palliative care. An overview of how social workers positively impacted patient care in these models provides an important context to better understand the possible roles of social work in home based primary care.

First, social work has been an important part of the interdisciplinary care of individuals receiving dialysis since 1976 when Medicare mandated dialysis clinics to employ social workers in order to help address the complex psychosocial needs arising from end stage kidney disease (Beder, 2008). Subsequent studies have documented multiple benefits from social work interventions in the care of dialysis patients including improved adjustment to dialysis and lower levels of depression (Beder, 1999) as well as improved quality of life (Beder, 2008). Similar benefits were noted for community dwelling patients recovering from stroke: social-work led biopsychosocial interventions improved quality of life, depressive symptoms, cognitive function, social engagement, and adherence to the care plan (Claiborne, 2006).

Second, social workers are often part of teams that provide treatment for depression and anxiety in community based medical settings (Archer et al., 2012). Several models of care attempt to bring these social work led mental health services into the home. For example, a social work led program of modified problem solving therapy delivered in the home significantly reduced depressive symptoms and improved health status in chronically ill

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elders with depressive symptoms (Ciechanowski et al., 2004). Social work led problem solving therapy has also successfully improved depression in elders with cardiovascular disease (Gellis & Bruce, 2010). Such interventions reaffirm the role of social workers in addressing mental health symptoms in primary care.

Finally, palliative care focuses on "providing patients with relief from the symptoms, pain, and stress of a serious illness"(Center to Advance Palliative Care, 2012). Palliative care social workers assist with assessment, counseling, liaison with local resources and agencies, training and development activities, staff support, and clarification of healthcare wishes and values (Brandsen, 2005; Monroe, 1994). Multiple published case studies describe the unique ways social workers can address the psychosocial needs of those living with serious illness. Such examples include a social worker helping to secure hospice services for an undocumented immigrant dying of cancer (Parrish et al., 2012), a social worker arranging for a seriously ill patient to return to his home hundreds of miles away (Creal, 2013), and a social worker facilitating a family reconciliation despite complicated family dynamics (Baker, 2005).

Background: MSVD Patients

MSVD cares for a diverse patient population with a high illness burden. According to a recent study of MSVD between 2008 and 2010 (Wajnberg et al., 2013) 75% of patients were women and nearly 70% were over the age of 80. Thirty six percent were white, 32% were Hispanic, and 22% were black. Forty three percent had Medicaid and 32% lived alone. Ninety one percent required assistance with at least one ADL and 99% required assistance with at least one IADL. Chronic diseases were highly prevalent with 49% of patients with dementia, 26% with depression, 18% with chronic lung disease, and 13% with cancer. Forty three percent reported severe symptom burden (Wajnberg et al., 2013).

Importantly, MSVD patients also have well documented unmet needs beyond those related to disease symptoms. A study of a subset of patients enrolled at MSVD in 2001 and 2002 indicated that at program enrollment, the following unmet needs were reported: 53% with homecare-related needs, 41% with needs related to daily chores, 38% with financial needs, 39% with housing-related needs, and 27% with transportation needs (Katherine Ornstein et al., 2009). In addition, levels of burden among caregivers were high as compared to reported values from other populations such as elders with dementia. Burden was highest among caregivers who spent over 40 hours a week providing care and those who helped with a greater number of activities of daily living (Reckrey et al., 2013).

Social Work at MSVD

The role of social workers at MSVD has expanded significantly since the program's inception in 1995 and social work is now an integral part of the MSVD program. The first social worker joined the MVSD program in 2001 as part of a grant funded initiative whose narrow focus was reducing burden of family caregivers and coordinating patient care within the hospital. Further grant funding and private donations allowed MSVD to expand their social work services and in 2004, the [XX] Hospital created a permanently funded social work salary line for MSVD. Social workers soon became more involved in the ongoing

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management of patient's complex psychosocial needs and a social work supervisor position was created in 2006. The social work supervisor is part of the MSVD executive committee and contributes to the development of the program's overall goals and direction. In addition to the hospital funded social worker, foundation and private donors have continued to support the social work program and the program has grown to three full time social workers and one social work coordinator. This means that there is currently one full time social worker for every 2 full time medical providers. In addition, one social worker hired though [XX] Hospital's Accountable Care Organization works exclusively with MSVD as a care coordinator.

For the majority of patients, social workers become involved in the care of MSVD patients when primary care doctors place a referral to social work using an Electronic Medical Record (EMR) based messaging system to request social work assistance with a specific patient care issue. A review of the reasons for referral to social work at MSVD between July 2005 and February 2008 extracted from the EMR revealed that the most common reasons for referral to MSVD social work were obtaining adequate benefits and coordinating home care services (Table 1). Other reasons for referral included: connection with community resources, end of life issues, and assistance with patient and caregiver coping (Table 1).

In addition, social workers can respond directly to the requests of patient or families who call the practice requesting assistance with non-medical issues. Each social worker is assigned to work with a team of medical providers at MSVD. This facilitates close working relationships between social workers and medical providers. Social workers are encouraged to meet with providers on a regular basis to review patients with ongoing social work needs.

In order to facilitate the social workers' patient assessment, a standardized social work initial assessment (Figure 1) was developed and integrated into the EMR. This assessment was designed to screen patients for a wide range of unmet needs as well as to document resources and support networks that patients already had in place. Importantly, the assessment template also includes space for the social worker's narrative assessment of the patient. In this section, information obtained from the standardized questions is synthesized with the social worker's own clinical impressions and a plan for intervention and follow-up is created.

Social workers' plans are tailored to meet patients' individual needs and may include interventions such as home visits, frequent follow up phone calls to agencies and family members, one-on-one counseling for patients, visits to hospitalized patients, collaboration with and referral to community agencies, and establishing advance directives. The social worker may be involved with a patient only 1–2 times for acute interventions or as frequently as several times per week for more complicated issues. Social workers at MSVD have the opportunity to develop long-term relationships with the neediest patients and they remain available to patients and families throughout the time that patients are enrolled in MSVD. In order to help describe the wide range of social work interventions employed at MSVD, we have included 4 case studies (Figure 2) that provide concrete examples of these interventions and their impact on patient care.

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In addition to the direct clinical roles described above, social workers have many other roles at MSVD. Social workers are involved with the education of new staff as well as the education of medical students, residents, and fellows from the [XX] School of Medicine. Social work students are placed at MSVD for social work internships each year. The social work team oversees the semi-annual newsletter sent to all patients. Each month, social workers lead a staff meeting where the team reflects on patients who have died and the team writes condolence cards to their families. Social workers also organize an annual memorial service for patients who have died while being cared for by the MSVD program. Finally, the social work program has developed several of its own initiatives designed to address issues important to the practice. Such initiatives have included development of protocols to help patients eliminate infestations of bed bugs and targeted efforts to update all patients' health care proxies.

Discussion

Social workers are an integral part of MSVD's successful model of home based primary care and we believe that the experience of the MSVD social work team is useful for other programs that wish to integrate social worker services into the medical care of homebound patients. Social workers at MSVD have a wide variety of roles and many of these mirror the roles of social workers in other community based medical settings: they help patients cope with their complex chronic illness and proactively address problems that inhibit quality care, they provide counseling to help address depression and anxiety among patients and caregivers, and they support patients and families who are facing serious and often life-limiting illnesses. Yet because of the diverse needs of the homebound patients at MSVD, social workers provide comprehensive care that isn't captured by any single one of these typical roles.

We believe that a key element to the success of the MSVD program is the social workers' individualized approach to care for each patient. While case managers and other health care professionals are well equipped to meet many of the psychosocial needs of individuals with complex illness, social workers' extensive training and broad scope of practice gives them a unique ability to both assess patients' psychosocial needs and develop collaborative treatment plans. At MSVD we have found that this flexibility and creativity is what allows the program to honor each patient's desire to remain safely in his or her home and we believe that this social work involvement should become the standard of care for home based primary care programs.

In the future we expect that the social work program at MSVD will supervise a growing number of social work interns. We also plan to expand social work led mental health services and to continue to build relationships with the rapidly changing array of community agencies and pilot programs that serve the homebound and those with complex chronic illness.

In order to support this growth, we understand that further research should address social work's impact on patient centered outcomes and building a base of evidence to guide further social work interventions (Egan & Kadushin, 1999; Rosenfeld, Taylor, Liu, & Volland,

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2008). However, because the MSVD program employs a team based approach to care it is difficult to tease out the impact of individual members of the care team. We have documented decreased unmet needs and decreased total caregiver burden among patients receiving home based primary care with MSVD (Katherine Ornstein et al., 2009) and believe that social workers play a key role in this. However, in the future we hope to refine our program assessments in order to more directly assess the impact of social workers at MSVD.

Successful incorporation of social workers into community based medical settings like MSVD can be challenging. Interdisciplinary collaboration, while considered positive for patients and providers, requires attention to team development and functioning and may be hindered by communication styles and personal characteristics (Abramson & Mizrahi, 1996). Yet with clarification of roles and clear articulation of team goals, social workers can be skilled liaisons with the community and help support patient's participation in their own care (Jani, Tice, & Wiseman, 2012). At MSVD, we hold regular interdisciplinary biweekly team meetings to foster effective communication and interdisciplinary team building.

The most critical barrier to further incorporation of social workers in community based medical settings is the lack of direct reimbursement for medical social work services by insurers such as Medicare (Davitt & Gellis, 2011). This often leads to reliance on grants or private funds to initiate social work interventions and unfortunately such initiatives often dissolve when funding ends. In addition, this lack of reimbursement for social work services contributes to the perception that such services aren't an integral part of medical care. However, we believe that as health care reforms seek to improve the quality of care while decreasing costs, development of innovative models of care will continue to grow and these models should prioritize increased social work involvement. The Independence at Home demonstration project is an example of how shared savings from cost-effective, home based care of frail elders can then be used to financially support the costs of a team based approach to care (Center For Medicare And Medicaid Innovation, 2012). Accountable Care Organizations and Patient Centered Medical Homes may provide further opportunities for funding of home based primary care programs that incorporate social work services into routine medical care (DeCherrie et al., 2012).

As the role of social workers in community based medical practices grows, continued evaluation of the role of social workers is needed. The complex biomedical and psychosocial needs of homebound patients are similar those of populations where social work involvement is routine, and we hope that the model of social work involvement at MSVD can serve as an example for those working to integrate comprehensive and individualized social work services in the medical care of their homebound patients.

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SOCIAL HISTORY:
Marital Status? Spouse name? Children? Contact information?
Years of Education? Occupation?
Substance Use?
 Tobacco? If yes, amount? If no, quit date?
 Alcohol Use? Drinks per Week?
 Drug Use? What Drugs?
Sexually Active?
Do you live alone? If no, who do you live with?
Do you have an Emergency Call Device (Lifeline) system?
Current Type of Housing? Public Housing/ Subsidized
 Apartment: How large is apartment? Is there an elevator?
 Assisted living: Name? Address?
 Private house: How many floors?

SOCIAL SUPPORT ENVIRONMENT:
Tell me about your family/other social supports.
 How often do they visit?
How do you socialize?
Are you involved with any community agencies? Name/ contact?
Is Adult Protective Services (APS) involved?
In the last 6 months have you seen a social worker? Psychiatrist?
 If yes, name and number? Can I contact them?
Do you attend a day-program? If yes, where? How often?

ENVIRONMENT CHECKLIST:
Problems such as:
 Bed Bugs? Problems with odors/pests/pets?
 Dangerous Stairs/Floors? Smoke alarm needed?
 Difficult to get to Home Entrance? Bathroom/ Bedroom?
 Problems with major appliances? Heating/ cooling?

HOME EQUIPMENT:
Home Equipment such as:
 Bedside Commode?
 Quad Cane? Hemiwalker? Wheelchair? Scooter?

FINANCIAL/INSURANCE:
Income per month? Social Security? SSI? Pension? Savings?
Insurance Information: Medicare? Medicaid? Private?
Are you having trouble paying for things like rent, food, meds?
Is there an agency or person who pays your bills? If yes, who?

COGNITIVE/EMOTIONAL:
History obtained from patient? Caregiver? Spouse? Child? Parent?
How is your memory?
In the past 6 months has anyone told you that you are forgetful?
Have you experienced any safety issues because of forgetfulness?
What activities do you receive help with? ADLs? iADLs?
Who helps you? Family? Friends? Please name.
 Home attendant/ Health Aide? Agency? Private pay?
 How many hours/ days? How long with current person?
If you do not receive help, do you need help?

EMOTIONAL:
Do you often feel sad? Nervous?
Are you currently caring for someone? If yes, describe.
Does anyone yell at you or insult you?
Have you ever been sexually assaulted or abused?
Have you ever been shoved, punched, hit, slapped?
Does anyone take your money?
Is there anyone that you are afraid of? If yes, describe.

FOR THE CAREGIVER:
Are you having difficulty meeting the patient's needs? Describe.
Do you often feel stressed? Describe.
Are you interested in a caregiver support group/ counseling?

TRANSPORTATION NEEDS ASSESMENT:
Uses assistive devices? Can use public transportation?
Uses transportation services provided by:
 Access-a-ride? Mount Sinai transportation?
 Managed care program? Community service project?
Requires an escort? Requires an Ambulance?

Figure 1.
Initial Social Work Assessment

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Case 1: When Guardianship is Necessary

Ms. J was 89 years old and the proud matriarch of a large family. She had been functioning well with daily help from a devoted home attendant despite her moderate and slowly worsening dementia. However, everything changed when her granddaughter and her 4 children moved into the small apartment. Her granddaughter prevented other concerned family members from visiting Ms. J and refused to meet with the medical team to discuss her care. It soon became clear that Ms. J's granddaughter had surreptitiously obtained power of attorney and was misusing her money. Adult Protective Services was called and determined that Ms. J needed a guardian. At the same time, Ms. J's landlords attempted to evict Ms. J because of complaints about her granddaughter. MSVD social worker advocated for a speedy guardianship process and a new senior housing apartment for Ms. J. They also mobilized Ms. J's other family members, provided support for them as they negotiated the difficult relationship with Ms. J's granddaughter, and made sure Ms. J was safe and cared for in her new apartment.

Case 2: Social Isolation and Self-Neglect

Ms. R lived alone in a 4th floor walk up apartment and was unable to leave the apartment on her own. She was a 78 year old widow with no children and no family nearby. She hadn't received medical care in years and was referred to MSVD by a local emergency room where she was seen for chest pain. Ms. R's once elegant apartment was now shabby and in disrepair and her personal hygiene was poor. Despite these unmet needs, Ms. R refused help. She was distrustful of those who tried to help her and was insulting and verbally abusive to aides who were assigned to care for her. After months of regular visits from the MSVD social worker, Ms. R slowly began to accept the help of the MSVD team. As this trust grew, the social worker was able to help her apply for Medicaid and facilitate her completion of a will and health care proxy. Her self-care improved and she was able to develop a relationship with a home health aide who helped make sure her household and medical needs were met.

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Case 3: Caregiver Stress

Mr. B was 92 years old and had advanced dementia, was bedbound, and spoke only a few words. His son was a devoted caregiver who had moved in with his father 15 years ago when he had become too ill to care for himself. His son attended to all of his father's personal care needs. While Mr. B's son only wanted what was best for his father, he would often yell at or hang up on physicians, nurses, and other healthcare workers. As Mr. B's health declined, his son's demands became more extreme and he often lost his temper when he received information about his father's health that he didn't like. Because the MSVD social worker's conversations with Mr. B's son could focus less on medical needs and more on his relationship with his father, she was able to recognize his role and validate the excellent care he provided for his father. This helped reduce some of his stress and the MSVD social worker helped Mr. B's son learn other ways to manage his stress. While Mr. B's son was extremely upset when his father approached the end of his life, he remained calm and was able to work with the healthcare team to provide his father with the end of life care at his home that Mr. B had always wanted.

Case 4: Preventing Nursing Home Placement

Ms. S daughter helped her mother manage her complex medical problems, but when her daughter passed away unexpectedly Ms. S moved into the small, cluttered apartment where her granddaughter lived with her husband and 3 children. Ms. S was alone most of the day. She received little support from her granddaughter and her health suffered. The MSVD social worker was consulted to help find alternative housing and arranged for her to visit a local supportive senior housing apartment building that she liked. But before this housing could be secured, Ms. S was hospitalized for heart failure and was then transferred to a sub acute rehab facility. It was determined that it was unsafe for her to return to her granddaughter's apartment and she prepared for a transition to a long term nursing home placement. However, the MSVD social worker remained involved with Ms. S's care and was able to expedite her housing application and advocate for her to return to the community in the senior housing. Ms. S moved into her new apartment and the continued to receive care from the MSVD team in the community.

Figure 2.
Social Work at MSVD

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Table 1

Reasons for Referral to Social Work Program

Reason for referral	Number of referrals	Percentage of referrals*
Securing benefits	224	33%
Home care	173	26%
Community resource referral	68	10%
Caregiver coping issues	68	10%
Housing	45	7%
End of life issues	39	6%
Abuse/neglect	33	5%
Patient Coping Issues	32	5%
Relationship issues	23	3%
Other Issues**	91	14%

*Percent totals >100 since more than one reason for referral can be given per case

**Other issues include arranging care of pets, arranging cleaning of cluttered apartments, coordinating home based recreational services, assisting with moving apartments, etc.